

SELF-CARE GUIDE



Visiting Nurse Service of New York

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INTRODUCTION HIV/AIDS



We want to help...

The Visiting Nurse Service of New York has been providing care for people with HIV/AIDS since 1981. Our staff continuously receives education regarding your special needs. We not only want to provide home care services, but also teach you how to take care of your health and manage signs and symptoms that affect your comfort and well-being.

The information we are sharing with you is based upon research and years of experience caring for people with HIV/AIDS. We also listen to our patients and their caregivers. They tell us what their problems are, what works, and what doesn't!

Preventing problems...

Our patients often ask us if there is anything they can do to prevent certain problems.

The answer is yes. Taking your medications as prescribed, eating healthy foods, taking proper care of your skin and mouth and getting exercise are all ways you can avoid some of the major complications of HIV.

Managing your symptoms...

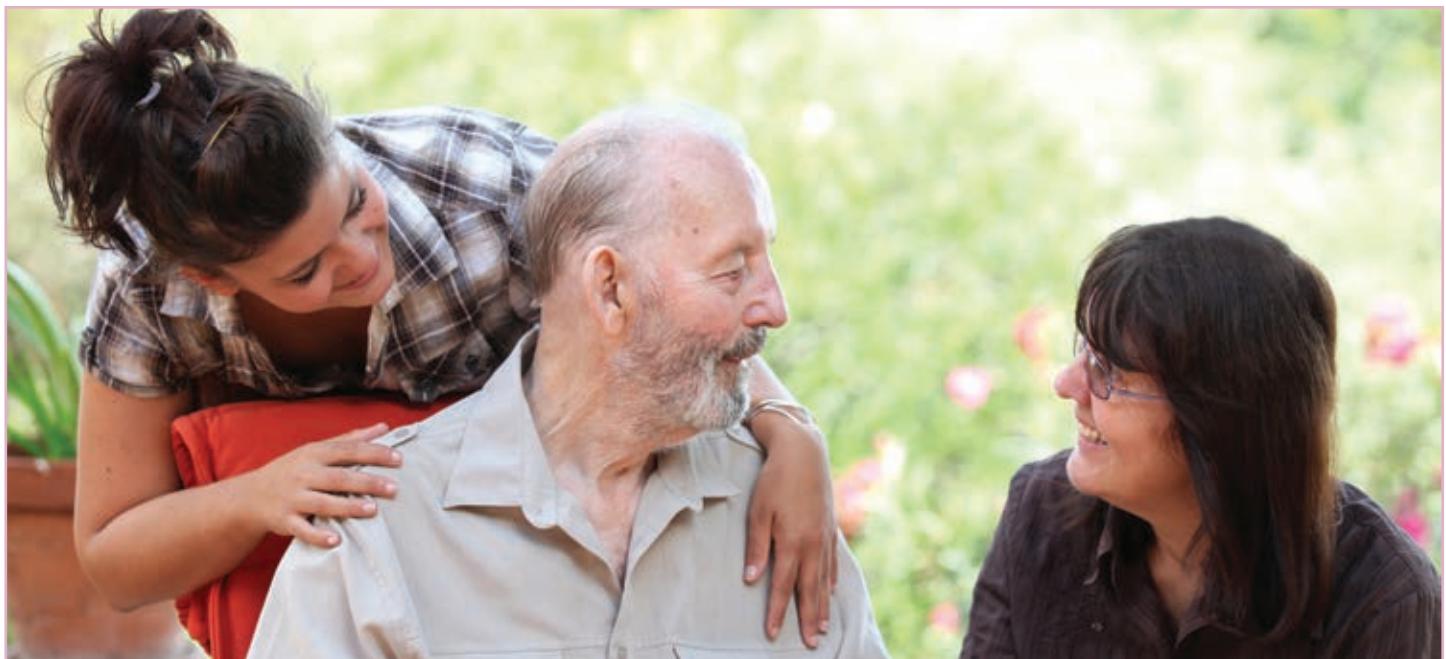
We have studied the symptoms most often seen in people with HIV/AIDS. Sometimes the symptoms come and go. Sometimes they stay around for a while. The purpose of this book is to help you learn how to control these symptoms rather than let them control you.

In some cases you can prevent symptoms or at least keep them from getting worse. Keep this book around so you can look up information when you need it. Certain suggestions can help with a number of symptoms. These suggestions are repeated in the book.

HIV and shame: HIV is a disease caused by a virus. You do not have to feel ashamed for having this illness. If you have no one you can talk to about this, speak with your health care provider for a referral to a community-based organization where you can get assistance and meet other people who are living well with HIV.

Understanding HIV

Maintaining your health depends on how well your immune system is working. Your immune system is made up of special blood cells that protect the body from germs that cause infections. The special blood cells that direct the activity in the immune system are called T-cells (also called CD4 cells).



When a person gets infected with the Human Immunodeficiency Virus (HIV), the virus infects and kills the T-cells. HIV kills these cells slowly over a period of years. Unless a person gets tested for HIV, they aren't usually aware that they are infected. As T-cells decrease, however, the body loses its ability to fight infection and the person gets sick.

The normal T-cell count is 500-1600. People with HIV can have low T-cell counts as HIV destroys these cells. Sometimes the T-cell count can even drop to zero. When the T-cells fall below 200, the person with HIV infection has less protection from disease, and can develop infections, or in some cases, cancer.

When this happens the person is diagnosed with Acquired Immune Deficiency Syndrome (AIDS).

HIV causes overstimulation of the immune system which then becomes weakened or burned out. This may lead to damage to the cells of the heart, liver, kidney and bone. Your primary care provider will monitor your health so if you develop any of these conditions, you can be treated.

Being HIV positive means that you can give the HIV infection to someone else through unprotected (unsafe) sex, or by sharing needles or works if you use drugs. HIV can also be transmitted from a mother to her child during pregnancy, during delivery, or after her child is born through breast feeding.

Preventing the Transmission of HIV



I **HIV is spread through blood, semen, vaginal secretions, breast milk and any body fluids that contain blood.**

HIV transmission can happen through unprotected anal, vaginal or oral sex. Unprotected sex is sex without a barrier such as a condom. HIV can also be spread by direct exposure to blood like sharing needles to inject drugs. Infected women who become pregnant may also infect their babies.

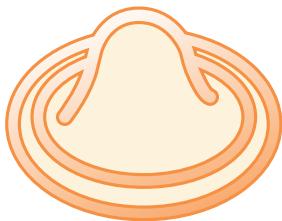


II **HIV is spread through unprotected (unsafe) sex. Some important reasons for practicing safer sex include:**

A So you don't get an infection from your sex partner. Even if your sex partner is HIV-positive, by not practicing safer sex you can give each other additional infections, including drug-resistant HIV. This could make it more difficult to treat the HIV in your body with medication.

B So you don't infect other people with HIV.

Preventing the Transmission of HIV

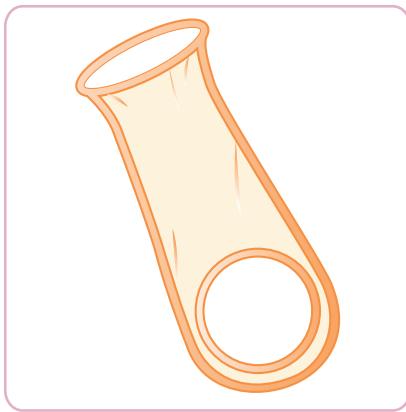


III Safer sex includes:

A Using a latex condom (rubber) to cover the penis during intercourse (penetration) in the vagina and in the anus.

- If you or your partner is allergic to latex, polyurethane condoms are available
- Remember to check the expiration date printed on the condom wrapper
- Don't keep condoms around heat or in your wallet
- Use plenty of water-based lubrication (lube) like K-Y Jelly or Wet when using condoms. Without the lubrication, the condom can tear more easily. There are many lubricants available. Just make sure to read the labels. The labels will tell you if the lubricant is safe to use with latex condoms.
- Do not use oil- based lubricants like Vaseline or baby oil. They will cause the latex condom to rip
- Lubricants containing nonoxynol-9 may cause irritation in your genital area, which could increase the risk of transmitting HIV
- Check condom for damage before using
- Be careful when opening condom package to prevent tearing the condom
- Prevent air bubbles from forming by holding the tip of the condom, when placing on penis
- Leave space at tip of condom for semen to gather, then add lubricant

Note: Having sex when you drink alcohol or take drugs can be a problem because you may not be able to make good decisions and will not practice safer sex.



B Using a female condom: If a man won't wear a regular condom (rubber), women can use a female condom to protect themselves. The female condom is made from polyurethane. Both Rite Aid and Walgreens stores carry the female condom. You can also go online at mayerlabs.com for more information.

This information is very important. If you don't understand any part of it, ask your health care provider to explain.

C Using a dental dam: when performing oral sex on a woman. (If you don't have a dental dam, plastic wrap can protect you; however, do not use the microwaveable kind because it has tiny holes in it.)

D Using a condom (rubber) when performing oral sex on a man.

E If you do have oral sex without a condom or a dental dam, avoid letting someone have an orgasm (cum) in your mouth. If you have any openings or cuts in your mouth, avoid oral sex until your mouth has healed.

F Using a dental dam (or non-microwaveable plastic wrap) for oral-anal contact (rimming).

G Avoiding douching because it reduces the normal protection found in the vagina.

H Dry kissing. Even open mouth deep kissing (French kissing) is not likely to transmit HIV as long as there are no open sores or cuts in either person's mouth. Avoid brushing teeth, flossing, or using strong mouthwash before deep kissing or oral sex. Mouthwash kills germs but it also kills some of the protection in your mouth. Because you might also have cuts or openings in your mouth after seeing the dentist, avoid deep kissing or oral sex until your mouth is healed.

I Erotic books, videos or sex toys. Sharing sex toys with a partner is not considered safe. If you do share toys, make sure to wash the toys thoroughly before sharing and cover with a new condom for each person.

J Masturbation, phone sex, and fantasy will not transmit HIV.

IV Abstinence (no sex) is a sure way of not transmitting HIV.

Preventing the Transmission of HIV

V HIV is transmitted through sharing needles to inject drugs.
If you do inject drugs:



- A Use a new sterile syringe obtained from a reliable source for each injection.
- B Ask your primary care provider for information about Needle Exchange programs. Needle Exchange programs will give you free clean needles.
- C You can also buy clean needles at certain pharmacies.
- D Don't share your needles, syringes, cookers or other "works" with anyone else. Remember to dispose of your needles and works in proper containers so no one gets stuck! You can use a designated "sharps container" from the hospital or a thick plastic laundry soap container with a handle. Remember to label the container "SHARPS" to avoid confusion and injury.

E If you can't get to the needle exchange or the pharmacy, cleaning your works is another option. (New, clean needles are the safest.) Here is how to clean your injection equipment:

- Rinse the needle and syringe with cold water several times (hot water will cause blood to clot, making it harder to remove). If you're using a detachable needle and syringe, you might want to take the equipment apart to clean it more thoroughly. Be sure to discard the water you use to rinse the equipment.
- Flush the needle and syringe with undiluted household bleach. Be sure to fill the syringe all the way up. Keep the bleach in the syringe for a full two minutes while shaking it. Discard the bleach.
- Thoroughly rinse the needle and syringe with clean, cold water to remove any remaining bleach. Discard the water.

VI HIV can be transmitted from mother to child through pregnancy, during delivery and through breastfeeding.

If you are pregnant, or thinking of getting pregnant, read worksheet #3 – Getting Pregnant.

VII If someone is caring for you in the home, make sure they:



- A** Always wash their hands well before and after caring for you.
- B** Wear latex gloves if they come in contact with your blood or other body fluids. (Note: There have been no documented cases of HIV being transmitted through saliva, sweat, or tears.)
- C** Clean up spills of blood or body fluids with a solution of one part bleach to 100 parts water. That is $\frac{1}{4}$ cup bleach to 1 gallon of water. Once mixed, this solution is good for 24 hours.

Taking Care of Your Health

| You can prevent health problems.

The basics include:

A

Pay attention to how you feel and how your body feels. If you develop a new problem, tell your healthcare providers.

B

If you are on HIV medicines, always take them the way they are prescribed.

C

Even if you feel better, continue to take your medications.

D

Make sure you keep your clinic and medical appointments.

E

If you smoke, ask for help in stopping.

F

Eat healthy foods every day.

G

Get some exercise every day.

|| Signs and symptoms that need to be reported include:

- A** Changes in vision
- B** Shortness of breath
- C** Rashes or sores on the skin
- D** Fever and/or night sweats
- E** Trouble swallowing
- F** Headaches, dizziness, seizures
- G** Bleeding gums, blood when you go to the bathroom, vaginal bleeding
- H** White stuff or sores in or around your mouth
- I** Pain anywhere in your body
- J** A new cough
- K** Weight loss
- L** Diarrhea
- M** Numbness or tingling in your arms or legs
- N** Redness or itching anywhere on your body
- O** Trouble remembering things

Taking Care of Your Health



III Health Maintenance and Screenings

- A** If you are sexually active, get screened for Sexually Transmitted Infections (STI), for example, syphilis, gonorrhea, chlamydia, once a year.
- B** If you have anal sex; have an anal Pap smear once a year.
- C** Women need to have a Pap smear every six months in the year after HIV diagnosis. If the results of both are normal then have a PAP once a year.
- D** Get tested for tuberculosis every year.
- E** Ask your healthcare provider about getting the flu shot every fall.
- F** It's important to get the Pneumococcal Vaccine every five years. This can help protect you from getting pneumonia.
- G** Get an eye exam yearly. If your T-cells are below 50, have an eye exam every 6 months.
- H** See a dentist once a year for an examination of your mouth.
- I** Get a colonoscopy at the age of 50. If you have a close family member (mother, father, sister, brother, or child) with a history of colon cancer or polyps, get it done earlier.

J There are several ways you can protect your liver. You can get tested for Hepatitis A, Hepatitis B and Hepatitis C.

- Vaccines are available to prevent getting Hepatitis A and Hepatitis B.
- There is no vaccine for Hepatitis C.
- If you have either Hepatitis B or Hepatitis C, there are medications available to help treat them.

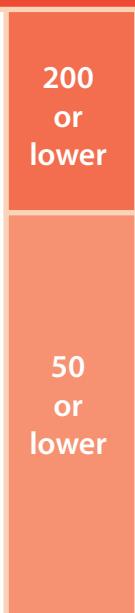
K Ask your health care provider if you need to get vaccinated for:

- Human Papilloma Virus (HPV)
- Measles, Mumps, Rubella (MMR)
- Varicella (chickenpox)

IV T-cells (*also called CD4 cells*)

Remember T-cells are part of the immune system that helps protect against infections.

The higher T-cells, the better



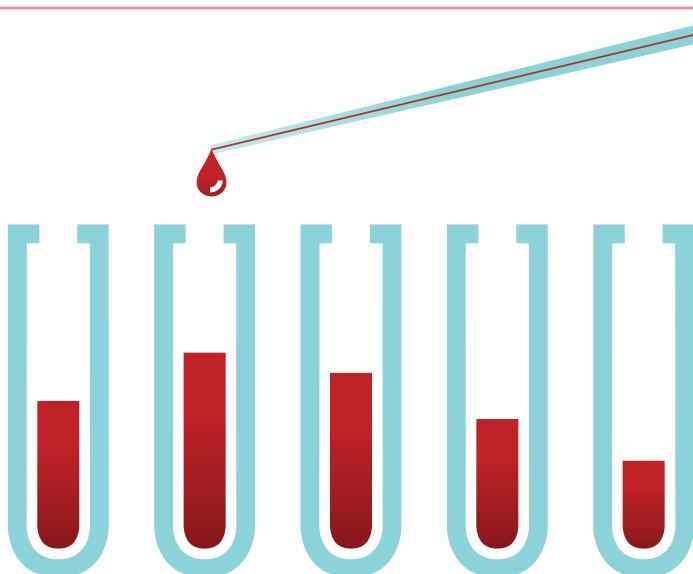
A The higher your T-cells, the better your body is able to fight off infection.

B If your T-cells are around 200 or lower, you need medication to prevent PCP (Pneumocystis Carinii Pneumonia). Without this medication, you are at risk for getting this type of pneumonia.

C If your T-cells are around 50 or lower, you need medication to prevent MAC/MAI (Mycobacterium Avium Intracellulare Complex). Without this medication, you are at risk for getting MAC/MAI.

D If your T-cells are around 50 or lower, you need to have your eyes examined every six months to protect from CMV Retinitis (Cytomegalovirus), an infection of the eye.

Taking Care of Your Health



V Viral Load Tests

- A** A viral load test is a simple blood test to determine how active the HIV virus is in your body and to how well HIV medications are working. It tells us how much of the virus is in a small amount of blood. The result is reported in “copies per milliliter” (abbreviated ml).
- B** When HIV is uncontrolled in the body, the viral load can be very high. Sometimes the viral load can go over a million copies/ml. Having a high viral load can be hard on your body and can make it hard for your T-cells to fight off infections.
- C** When you take HIV medications as prescribed, they control HIV activity and your viral load may go down to very low levels. This can make it easier for your T-cells to fight off infections.
- D** When the drugs work very well, the viral load can go down to “undetectable” levels. Undetectable viral load does not mean you are cured. You still have HIV, but the infection is very well controlled. This is great news, but you can still pass the virus to someone else through unprotected sex, sharing needles, and from mother to child during pregnancy, delivery or breast-feeding.



VI HIV and Getting Older

- A** As you live longer with HIV, you may get some of the conditions mostly seen in older people.
- B** Heart, blood vessel, kidney and bone diseases, diabetes and cancer may develop. These conditions are more common in people with HIV.
- C** Having HIV and managing your health creates some unique challenges. It is very important to see your health care provider regularly to help you manage any condition that may develop.
- D** Older people may be on a lot of other medications which may interact with each other and with HIV medications (see page 24). Tell your primary care provider all the medications you take so that interactions can be monitored and you can get help managing any side effects.
- E** As mentioned on page 10, get a colonoscopy. If a close family member (mother, father, sister, brother, or child) had colon cancer or polyps before age 50, have a colonoscopy before you are 50 years old.
- F** In addition to the above screenings and vaccinations, ask your health care provider to:

- Test your cholesterol, lipid, and blood sugar levels
- Test your Vitamin D level
- Check testosterone levels
- Screen you for Osteoporosis

- G** Ask if you are able to take the herpes zoster vaccine to protect you from getting shingles. If your T-cells are too low, you will NOT be able to take this vaccine.

Taking Care of Your Health

Concerns for Women



It can be difficult and even scary to go for a gynecological exam but it is very important to get a yearly checkup. Find a practitioner you feel comfortable with and talk to them about your fears and concerns.

I HIV and Menstrual Problems

Many women living with HIV experience changes in their menstrual cycle.

A Changes you may have include:

- Irregular periods
 - Difference in how often
 - Difference in how long
 - It may be lighter or heavier
- Missed periods
- No period for more than 90 days
- Spotting between periods

B Irregularities to your periods happen less often if you have a high CD4 T-cell count and are taking HIV medications.

C It is important to try to find the cause of any menstrual problems so discuss any changes in your menstrual cycle with your health care provider.

D Remember to get a Pap test every 6 months the year after your HIV diagnosis. If both are normal, you should have a Pap every year after that.

Other problems that can occur:

|| **Vaginal candidiasis, also called yeast infection, is a very common problem in HIV-infected women. The problem can occur or get worse when you take antibiotics.**

A The signs and symptoms include:

- Severe vaginal itching
- A yellowish-white discharge
- Red, irritated skin around the vagina

Note: Always report any vaginal problems to your health care provider. The problem could be another type of infection.

B To minimize yeast infections:

- Try eating at least 8 ounces of yogurt every day. The label on the container must say it contains lactobacillus acidophilus or L. acidophilus. If you don't like yogurt, you can buy acidophilus capsules at a health food store.
- Lower your intake of sugar, processed foods and fast foods.
- Avoid tight fitting underwear and pantyhose. Try to wear cotton underwear or underwear with a cotton crotch.
- Try to wash underwear in hot water using bleach and iron the crotch of the underpants.
- Avoid wearing tight fitting pants.
- Change menstrual pads frequently. Use unscented, non-deodorized pads.
- When wiping the vaginal area, always wipe from front to back.
- Avoid douching and feminine hygiene products.

C Traditional treatments include:

- Anti-fungal creams and/or vaginal suppositories prescribed by a health-care practitioner or purchased over-the-counter at a drugstore
- Anti-fungal medicine prescribed by your health care provider that you take by mouth

D Alternative "natural" remedies include:

- Acidophilus vaginal suppositories (available in health food stores)
- Plain, unsweetened yogurt inserted with an applicator into the vagina

Taking Care of Your Health

Concerns for Women

III HIV-infected women are also more prone to develop Pelvic Inflammatory Disease, also known as PID. PID is a severe infection of the female reproductive organs.

A The signs and symptoms include:

- Cramping pain in the lower abdomen
- Fever and chills
- Vaginal discharge that has pus in it
- Vaginal bleeding
- Nausea and vomiting

B Immediate medical treatment is needed if you have any of the above symptoms

C The risk of getting PID can be reduced if you:

- Always use a latex or polyurethane condom for vaginal sex
- Avoid using an intrauterine device (IUD). There is a greater risk of PID in women who use IUDs

IV Women with HIV have a higher rate of abnormal cells on the cervix and cervical cancer than other women. Invasive (advanced) cervical cancer is preventable.

A It is very important that you have a vaginal exam and Pap smear at least once a year. Some types of vaginal warts increase the risk of an abnormal Pap smear and cervical cancer. Health-care providers often recommend that HIV-infected women get a Pap smear every six months.

B Signs and symptoms that may indicate cervical cancer include:

- Vaginal bleeding after intercourse
- Blood-tinged and/or foul-smelling vaginal discharge
- Irregular menstrual periods
- Pain in the abdomen, back or leg
- Weight loss

V Women Over 50

Use condoms even though pregnancy may no longer be a concern. The lining of the vaginal walls are thinner and are more likely to tear during intercourse. Tears in the vaginal wall results in increasing the chance of being re-infected with HIV and acquiring other sexually transmitted infections.

Getting Pregnant



Getting Pregnant

I The decision whether or not to have a child belongs to you.

If you are considering getting pregnant it's important to speak with your health care provider. Your HIV medications may need to be changed.

II If you are thinking about having a child, there are some very important issues to consider, including:

- A** Waiting until your immune system is at its strongest. Your T-cell count should be as high as possible and your viral load as low as possible. This increases the chances of having a healthy baby. Remember, taking your HIV medications at the same time every day may help you increase your T-cell count and lower your viral load.
- B** If your T-cell count is low, there is a possibility you may get sick during your pregnancy. Be sure to speak to your health care provider to determine the best medication to use while you are pregnant.
- C** Your baby may have to take HIV medications for about 6 weeks after birth even if he/she does not have HIV.
- D** Most babies in the United States born to HIV infected mothers are not HIV+, but a few are. It may take up to six months after the baby is born to know if he or she is infected.
- E** If you are using drugs or alcohol, you may want to seek treatment as this could harm your unborn baby.
- F** Who will take care of the baby if you or the father, or both of you, get sick?
- G** If you and/or the father die, who will become the guardian? This will require legal assistance. There are community-based organizations that can help with this. Ask your health care provider for assistance.

Getting Pregnant

III If you are already pregnant:

- A** Make sure you and your baby get prenatal care.
- B** Get tested for syphilis and other sexually transmitted diseases to help prevent passing them on to your baby.
- C** Ask your doctor about taking HIV medication, including AZT, during pregnancy. This medication has been shown to reduce the risk of your baby being infected with HIV.

IV If you want to avoid getting pregnant:

- A** Always use a condom.
- B** If you choose to use any other form of birth control, you need to use a condom to prevent the exchange of body fluids between you and your partner (even if he also has HIV). These include:
 - Birth control pills; hormonal patches, implants or injections; vaginal rings
 - Sponges, spermicidal gels, creams or foams
 - Diaphragms, cervical shields
 - Intrauterine device (IUD)

V If you want to get more information about these matters, talk to your health care provider and he/she will get the information to you.

If you have children:

A Who will take care of your children if you go to the hospital?

- Home health aides and home attendants are not allowed to stay alone with children.

B Have you planned for guardianship (person you choose to care for your children if you are unable to)?

C Are any of your children infected with HIV?

D Do your children need to be tested for HIV?

E Do your children know about your HIV diagnosis?

F Do you or your children need help in coping with your diagnosis? Remember teenagers often express anger when they are really fearful.

If you need information or want help with these matters, your health care provider can refer you to community-based agencies.



Medications



The importance of HIV medications

- A** Before you decide to take HIV medications you may want to look at the pros and cons. Write them down on paper. This can help you decide if you are ready to start taking medications.
- B** HIV medications attack the virus in your body. They decrease the amount of virus in your blood (the viral load). This may help your T-cell count go up. Remember, the higher your T-cell count, the better your body is able to fight off infection.
- C** Follow the directions for each medication carefully. Some must be taken with food and some on an empty stomach. Always follow the instructions your prescribing practitioner gives you or the drug may not be absorbed from your stomach into your bloodstream.
 - Do not change the hour or number of times per day that you are supposed to take HIV medications.
 - If you experience side effects, tell your health care provider. There are ways to control side effects. This booklet has information on how to manage some side effects.
 - Store the medicine as directed. For example, some medicine needs to be stored in the refrigerator.
 - HIV medications interact with many other drugs including non-prescription drugs, herbal or natural remedies, and recreational or street drugs. Check with your prescribing practitioner or the pharmacist before taking any new medications.

Medications



|| Adherence: Taking medications as prescribed

Tips to help you remember to take your medications:

- Use a pre-pour box to pre-fill medications
- Use cell phone reminders, or medication or radio alarms
- Ask a friend or family member to remind you
- Use a calendar to mark off each time you take the medication
- Ask your pharmacist about blister packs. Blister packs have all your pills pre-poured by the time you need to take them

If you decide not to take the medications as prescribed by your provider, let him/her know.

Not taking the medications as prescribed can lead to drug "resistance."

This means that the drugs may no longer control HIV. The choice is yours but it helps to let them know that you stopped taking your medications. This can help your provider take better care of you.

Note: If you decide to take the medications to control HIV, it is VERY IMPORTANT to take them at the same time every day. Remember, skipping doses and/or skipping days can cause drug resistance. Drug resistance means the medications have less or no power to fight HIV.

Alcohol and Drug Use



Treating HIV can be more complicated if you are using alcohol or drugs on a regular basis. Unfortunately, it is sometimes difficult to find someone to talk to about this. People can seem judgmental and uncaring. However, it is important to deal with alcohol and drug use because it affects your health.

| Drinking alcohol can be a problem because:

- A** It can damage your liver or pancreas. If you continue to drink while taking certain medications that treat HIV, TB or MAI, you could increase your risk of damaging these organs.
- B** If you have hepatitis, it's important to speak with your health care provider about alcohol and drug use. With hepatitis, your liver is more sensitive and can be more easily damaged by alcohol and drug use.
- C** In order for your HIV medications to be effective, it's important to take them at the same time every day. Sometimes drinking alcohol can make you forget to take them.

If you can't stop drinking, try to cut down. If you feel your drinking is a problem, ask your health care provider about getting help.

Alcohol and Drug Use

II Using drugs can be a problem because:

- A** Intravenous (IV) use of drugs such as heroin, speed or cocaine can cause liver, heart and kidney damage. It can greatly increase your risk of getting infections.
- B** Smoking and/or snorting cocaine, crack or speed can damage your lips, mouth, nose, heart and lungs. It can also lead to frequent infections. Cocaine use can actually raise your viral load.
- C** Street drugs can interfere with the effectiveness of your HIV medications. They can also make you forget to take them on schedule.

If you would like to talk with someone about your drug use, there are many community-based agencies that may be able to help you. Ask your health care provider for more information.

III If you do use drugs and/or drink alcohol, please:

- A** Make sure to dispose of any injection equipment in a proper sharps container so no one gets stuck with a used needle.
- B** Do not ask any home care staff to buy you drugs or alcohol.

Personal Care

I Skin Care:

Your skin is a very important protection against infection. Proper care can prevent problems. Things you can do to care for your skin include:

- A** Shower with warm water. Hot water can dry out your skin. Ask your health care provider about getting a shower seat so you can sit down and relax during the shower.
- B** Wash with a moisturizing soap such as Dove, Caress or Aveeno.
- C** Pat your skin dry with a towel rather than rubbing.
- D** Use body creams or lotions while your skin is still damp to keep moisture in the skin.
(Vaseline works well and is inexpensive.)
- E** Keep your home humid. Use a humidifier during the winter. Remember to clean it as often as the manual indicates. If you don't have a humidifier, keep a pot of water on or near the radiators. Change the water every day and clean the pot.
- F** If you sweat a lot, wear cotton underwear.
- G** Wash your hands well with soap and water:
 - After going to the bathroom
 - Before and after handling food
 - Before eating
 - After handling pets

II Mouth Care:

Mouth care is very important but should not be done before sex because it can reduce the normal protection found in the mouth. Things you can do to care for your mouth include:

- A** Clean your mouth after meals and before going to bed.
- B** Clean your mouth in front of a mirror, so you can see what condition it's in.
- C** Use a soft toothbrush and brush gently; floss daily.
- D** Avoid very strong commercial mouthwashes that make your mouth burn.
- E** See a dentist yearly.

Pets in the Home



I Pets are very important and may be a comfort to you.
Keep your pet healthy by doing the following:

- A Keep your cats indoors so they don't get infections from other animals.
- B Keep your dog on a leash when you go outdoors for the same reason.
- C Don't feed your pets raw meat. It may have germs and make both of you sick.

II To keep yourself healthy:

- A If your T-cells are under 200, have someone else clean up after your pets, whenever possible.
- B If you have to clean the litter box, bird cage, fish tank or clean up after turtles, lizards or snakes, wear disposable latex gloves and a mask. Wash your hands immediately afterwards.
- C When you pick up after your dog, wash your hands when you get home.
- D Avoid letting your pet lick your mouth or any open cuts or wounds. Don't let pets sit on your pillows.
- E Always wash your hands after handling your pets.

Food and Water Safety

Food and water can carry germs that may cause serious infections in people living with HIV, especially when T-cells drop below 200. Following some basic guidelines may help prevent these infections.



Boiling is the best and least expensive way to make sure your drinking water is safe

WATER SAFETY

Even though the water in New York City has chlorine to purify it, some germs are not killed by chlorine. For most people, New York City tap water is safe to drink. But if you have HIV, you should follow the guidelines below because some germs are not killed by the chlorine the city adds.

To avoid infection from water:

- A** Most water filters you can buy at the store do not filter out all the germs. Boiling is the best and least expensive way to make sure your drinking water is safe.
- B** At home, use boiled water for drinking, making ice cubes, and cleaning fruits and vegetables. Boiling water for 1 minute will kill germs. This may sound like a lot of extra work. Try getting into the habit of boiling water each morning in a large pot. Keep the lid on while boiling and while it's cooling so it doesn't evaporate. If you notice a taste to the water after boiling, you can pour it through a regular water filter like Brita or Pur to make it taste better. If you use a filter, make sure you replace it as directed by the manufacturer. Remember, make ice cubes with this as well.
- C** When you are away from home, especially out of the United States, drink bottled water. Soft drinks in cans and bottles are safe.
- D** Soft drinks from a fountain in restaurants or bars are made with water that hasn't been boiled. Avoid ordering these. The same is true for ice you don't make at home.

Food and Water Safety



- A** Eat and drink only pasteurized juices and dairy products. Almost everything sold in the grocery store will be OK.
- B** Cook meats, fish and poultry thoroughly. They should be cooked until there is no pink. Use a meat thermometer to ensure an internal temperature of 180 degrees for poultry and stuffed meats and 170 degrees for all other meats.
- C** When barbecuing, always pre-cook meat first.
- D** Remember to wash your hands immediately after handling raw meat.
- E** Have 2 cutting boards: one for meat, chicken, and fish; the other for everything else.
- F** Wash utensils used for uncooked meats before using on other foods.
- G** Do not eat raw or partially cooked eggs.
- H** Wash all fruits and vegetables thoroughly before eating. If T-cells are below 200, use boiled water. Peeling the skin also helps make them safer.

FOOD SAFETY

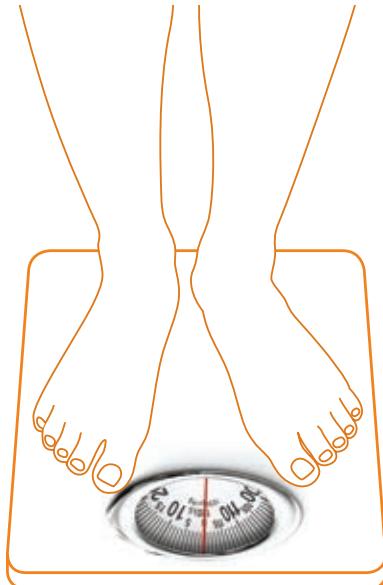
To avoid infection from food:

- I** When using a microwave, follow directions carefully, especially standing time, which helps to heat food evenly.
- J** If you have cuts or sores on your hands, wear disposable latex gloves when handling food.
- K** Refrigerate leftover food right after finishing your meal. If you have meals delivered, be sure to refrigerate all food that is not eaten right away.
- L** When food shopping:
 - Place raw meat, fish, and poultry in plastic bags to prevent blood and juices from leaking onto other foods.
 - Read expiration dates to prevent buying foods that are out of date.
 - Refrigerate perishables as soon as you get home from the store.
 - Avoid purchasing prepared foods if you do not know if it is fresh or how it is made, for example, salad or hot foods from a deli counter.

Nutrition

Overweight

The following information is for people who are overweight or do not want to gain any more weight.



If you have Diabetes, Kidney Disease and/or Heart Disease, you should go to the websites listed below, rather than using the information on this page.

• DIABETES

www.diabetes-guide.org/
american-diabetes-association-diet.htm

• KIDNEY DISEASE

www.kidney.org/atoz/content/nutrickd.cfm

• HEART DISEASE

[www.heart.org/HEARTORG/GettingHealthy/
Diet-and-Lifestyle-recommendations_UCM_305855_Article.jsp](http://www.heart.org/HEARTORG/GettingHealthy/Diet-and-Lifestyle-recommendations_UCM_305855_Article.jsp)

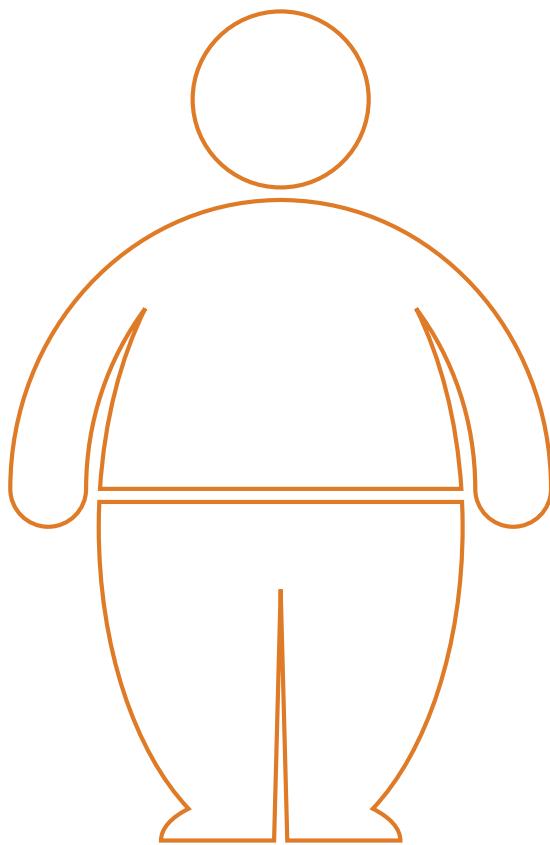
Most of your diet should be made up of foods that are good for you. You probably don't include food when you think of the things you do to keep yourself healthy, but it's an important part of your plan to stay well. Every day you should try to eat some of the following:

- A** Fresh fruit. It doesn't matter which you select. They're all good for you.
- B** Vegetables. Either fresh or frozen. Try to avoid canned as they often are high in sodium, which could increase your blood pressure.
- C** Nuts and peanut butter (avoid nuts that are heavily salted).
- D** Lean beef, lamb, pork, fish, chicken, turkey. All are fine as long as they aren't fried and you cut away the fat before cooking. You can bake, broil, roast or boil them.
- E** Grains (whole wheat bread, rice, barley, quinoa, grits, oatmeal, etc.)
- F** Low fat dairy products (1% milk, low fat yogurt, cottage cheese, reduced fat cheeses).
- G** Get in the habit of taking a multi-vitamin daily at the end of your largest meal.

Nutrition

Overweight

Many foods have “empty calories” which means that it’s easy to gain weight when you eat them AND they do not help your body do its job. You should limit these foods and have them as treats on special occasions or once or twice a week. They are:

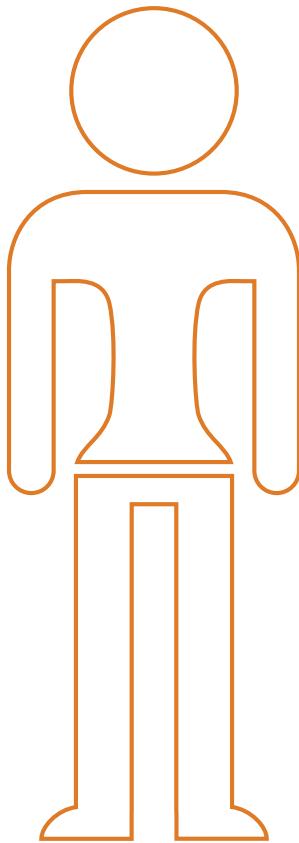


- A** Fried foods (like fried chicken, French fries, most Chinese food, doughnuts).
- B** Soda (except diet soda).
- C** Snack foods like potato chips, corn chips, Cheetos, etc. Pretzels are O.K.
- D** Fatty meats (bacon, sausage, salami).
- E** High fat dairy products (most cheeses, ice cream, sour cream, etc.)
- F** Cakes and cookies. Did you know that half of the calories in a sweet roll come from fat?
- G** The U.S. government will help you figure out how many “**empty calories**” a food has if you go to this website:
www.choosemyplate.gov/food-groups/emptycalories_count_table.html

Nutrition

Underweight

The following information is for people who are underweight or would like to gain weight.



If you have Diabetes, Kidney Disease and/or Heart Disease, you should go to the websites listed below, rather than using the information on this page.

• DIABETES

www.diabetes-guide.org/
american-diabetes-association-diet.htm

• KIDNEY DISEASE

www.kidney.org/atoz/content/nutrickd.cfm

• HEART DISEASE

[www.heart.org/HEARTORG/GettingHealthy/
Diet-and-Lifestyle-recommendations_UCM_305855_Article.jsp](http://www.heart.org/HEARTORG/GettingHealthy/Diet-and-Lifestyle-recommendations_UCM_305855_Article.jsp)

To gain weight, try the following:

- A** Try to eat as many times a day as you can, even if it's just a snack. Aim for 3 meals, plus 3 snacks. A good time to add a snack is at the end of the day, a few hours after dinner.
- B** Make your own milkshakes by mixing milk, soy milk, juice, or yogurt with any of the following: protein powder, peanut butter, ice cream, banana, fruit, or chocolate syrup.
- C** As a snack or when you can't eat a meal, drink nutritional supplements like Ensure, Boost or Juven. Ensure Plus or Boost Plus have even more nutrition than regular Ensure/Boost. All of them are lactose free.
- D** Snack on nuts and dried fruit. Keep a bowl of them in sight and take a few as you pass by.

Nutrition

Underweight

To gain weight, try the following (*continued*):

- E** Sneak extra fat into foods. For example, add a tablespoon of olive oil to a bowl of soup or a pat of butter to morning oatmeal.
- F** Try to eat more on days when you feel well. For example, if you're hungrier at one time of the day, like morning, learn to eat a big breakfast.
- G** Keep moving! It's easier than you think. Just walking to the store, or, if you're inside, making the bed or preparing a meal, count as exercise. So does lifting weights or riding a stationary bicycle. Go outside even if it's just to sit in a nearby park or walk around the block. Leaving your apt and/or being as active as possible. All of these activities should help increase your appetite.
- H** Participate in one of the many food service programs for people living with HIV. God's Love We Deliver delivers meals anywhere in New York City. Their number is **(212) 294-8102** or **(800) 747-2023**.

Along with the weight gain suggestions above, the following recommendations will help improve your nutrition.

If you're not eating a lot, it's very important that what you do eat is high in protein.

A major source of protein is animal products like meat, fish, chicken, eggs, and dairy (milk, yogurt, cheese).

There's also a lot of protein in soy products (soy milk, tofu, edamame), beans, and nuts.

- A** Prepare soup and hot cereal with milk instead of water.
- B** Get in the habit of taking a multi-vitamin daily at the end of your largest meal.
- C** If you have a history of dehydration, increase the amount of water you drink but do NOT drink either before or during meals as this will decrease the amount you eat.
- D** Learn to read the nutrition label on every packaged food. Once you're comfortable with the label, you can select foods that are more nutritious.

If you're having trouble eating because food doesn't smell or taste right, try the following:

- J** If smells bother you:

- If possible, keep windows open while cooking.
- Have a friend/relative cook at their home and bring the prepared food to you.
- Eat foods at room temperature.

Nutrition

Underweight

K You can increase the flavor of many foods with herbs (basil, oregano, rosemary, thyme, mint), spices (cloves, cinnamon), or lemon juice.

L If you have a metallic taste in your mouth:

- Brush your teeth before eating. If toothpaste doesn't help, try a baking soda and salt mixture.
- Eat citrus fruits like an orange or squeeze lemon juice on food.
- Marinate meat and poultry in fruit juices, barbecue sauce, or salad dressing before cooking.
- Drink more water to wash the taste away.
- Use plastic forks and spoons instead of metal ones.
- Take 50mg zinc/day. Check with your health care provider to see if this treatment is appropriate for you.

If you are too tired to cook:



Eat foods that are easy to prepare

A You may want to ask your health care provider about drinking specially prepared liquid supplements like Boost or Juven. These can be used as meal substitutes.

B If friends or family call and want to bring something over, have them bring some food. If possible, freeze some in airtight containers for later.

C When you feel better, cook meals that are easy to prepare. Store them in small containers so it's easy to reheat and serve.

D Eat foods that are easy to prepare such as frozen meals, cereal with milk, sandwiches, and eggs. You can have up to 7 yolks per week and as many whites as you want.

If you are having trouble eating because of pain or difficulty swallowing, or because chewing is uncomfortable, please refer to "Mouth Problems" on page 57.

Diarrhea

Diarrhea is a common problem with HIV infection. You can ask your health care provider for medication to stop diarrhea.

To help manage diarrhea you can also try these suggestions:

- A** Drink plenty of liquids to replace the fluid you are losing. Try drinking at least 8 eight-ounce glasses of liquid each day.
- B** Water is most important. You can also drink sports drinks like Gatorade, mixed with water, and salty broth.
- C** The BRAT diet is often helpful to reduce diarrhea because it helps bind you. It contains Bananas, white Rice, Applesauce and Toasted white bread or Tea (black, not herbal).
- D** Eat foods high in potassium such as bananas and potatoes. Coconut water has a lot of potassium.
- E** Choose foods like fish, chicken, cooked eggs, peanut butter, yogurt, noodles and cooked cereals such as farina and oatmeal.
- F** Alcohol, caffeine, and milk can make diarrhea worse. Therefore, avoid or at least cut back on the amount of these beverages you drink.
- G** Use nutritional supplements like Advera or Lipisorb which won't make your diarrhea worse. Some supplements do like Ensure or Boost. Ask your health care provider which is best for you.
- H** Instead of 3 large meals per day, try to have 5-6 small meals.
- I** Some people find that acupuncture can help relieve diarrhea.

Certain foods
can make your
diarrhea worse.



II Certain foods can make your diarrhea worse. They include:

- A** Greasy, fried, fatty foods
- B** Strong spices such as hot peppers, chili, curry
- C** Fruits, except raw apples, pears, and bananas
- D** Whole wheat or bran products, nuts
- E** Vegetables like beans, cabbage, cauliflower, broccoli, peas, corn, onions, kale, collard and mustard greens

III If milk or dairy products give you diarrhea, you can try:

- A** Avoiding them. You may have developed lactose intolerance. Lactose is a substance found in dairy products.
- B** Lactose-free dairy products. Even lactose-intolerant people can enjoy yogurt, hard cheeses (like cheddar) and Lactaid milk.
- C** Asking your health care provider about special tablets (Lactaid tablets) that you can take to reduce the problem. You can also buy lactose-free milk and cheese.

IV To prevent soreness and skin problems caused by diarrhea:

- A** Use a moisturizing soap like Dove or Caress to clean after bowel movements.
- B** Pat your skin dry and apply a thin coat of Vaseline or A & D Ointment. They will both soothe the skin and protect it from contact with moisture.
- C** Use liners in your underwear to prevent leakage and moisture from getting on your clothes.
- D** Use baby wipes to clean yourself after going to the bathroom. Remember to carry them with you when you leave home.



Nausea and Vomiting

Nausea and vomiting are common problems with HIV infection. You can ask your health care provider for medication to relieve nausea.

Here are some tips you can try to help you feel better:

- If you are prescribed a medication to relieve nausea, take it at least 30 minutes before you eat.
- Drink small amounts of clear fluids like ginger ale, water or clear broth.
- The less flavor, the better. Foods that are cold often have less flavor than foods served room temperature or hot.
- When you are nauseous, bland food is usually easier to digest. Try food like potatoes, rice, crackers, jello or yogurt.
- Try to avoid fried, greasy or spicy foods.
- Caffeine and products that contain lactose (like milk) may make you feel more nauseous.
- Some people find that sucking on a cold lemon or chewing on an orange peel helps.
- Drink ginger tea or eat ginger candy.
- Wear loose clothing to make you as comfortable as possible.
- Try not to lie flat for at least two hours after eating. If you do lie down, use a pillow to raise your head.
- Use a fan to keep the air moving if the room feels stuffy or hot.
- Eat 5-6 small meals rather than three large ones.
- Try to avoid liquids at mealtime as they may fill you up.
- Review all your medications, including vitamins, minerals, and herbs, as they may be making your problem worse.
- After vomiting, wash your mouth out with a baking soda, salt, and water mixture.

Constipation

Medication to relieve pain often causes constipation. If you cannot move your bowels easily or the way you normally do, let your health care practitioner know. Here are some suggestions for relieving constipation:

- Ask your practitioner to prescribe a stool softener and/or a laxative.
- Over the counter remedies such as psyllium husk fiber (Metamucil) can help. Remember to drink a full 8 oz glass of fluid with psyllium fiber. (Note: Psyllium fiber should NOT be taken at the same time as your prescribed medications. It should be taken at least two hours before or two hours after taking medications.)
- Add high-fiber food to your diet. Fruits and vegetables, whole grain bread, cereal, nuts, beans and dried peas all have lots of fiber in them.
- Try to avoid white bread and white rice when you're constipated.
- Remember to drink at least 8 glasses of fluid each day.
Sometimes drinking warm or hot liquids can help.
- Try to get some exercise. Ask your health care provider what exercise is best for you.
- For some people, drinking a cup of coffee will be an effective laxative.

Fatigue

Tiredness



Do you find yourself feeling tired or exhausted frequently?

If you do, talk to your health care practitioner. There may be ways to treat this.

| When you're tired, it is helpful to:

- A** Stop what you are doing and rest until you feel more energetic.
- B** Plan your activities wisely and rest in between. Do the important activities first. It is a good idea to plan only one activity on days that you have medical appointments.
- C** Take walks in areas where you know there are benches to rest, such as a park or shopping mall.

Fatigue

Tiredness

To conserve energy you can try to:

- A** Increase the amount of sleep you get, even with cat naps. If you have insomnia, do not take a nap within 6 hours of bedtime.
- B** Eat healthy foods. Food provides fuel for energy.
 - Small frequent meals are a better choice than three large, heavy meals, especially if you feel tired. When the meal size is smaller, it takes less energy to eat it.
- C** Exercise can help you build endurance and decrease fatigue. Ask your health care practitioner which exercise is best for you. Exercise improves how well your body uses oxygen. You don't have to jog or join a gym. Simple exercises include:
 - Stretching your arms and legs when you get out of bed
 - Walking up and down stairs, even if you start with only two or three steps. Try to increase the number of steps each time you do it
 - Sitting in a chair and holding a can of food in each hand while extending and flexing your arm muscles
 - Taking a walk, going a little farther each time

Other suggestions:

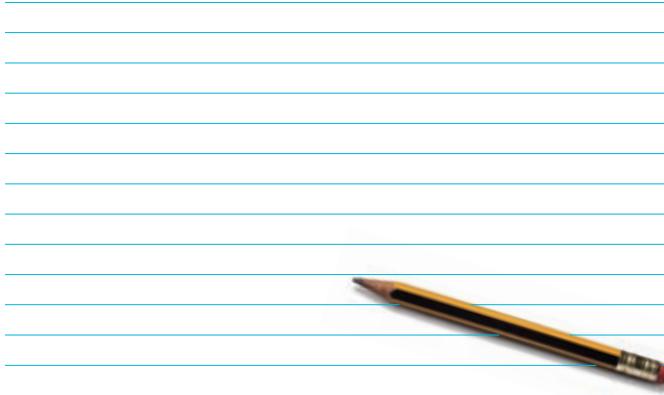
- Schedule important activities at a time of day when energy level is high
- Pace yourself. Alternate restful activities with more strenuous ones
- Don't be afraid to ask for help



Exercise can help you build endurance and decrease fatigue.

Fatigue Rating Scale

A self-rating scale can help you decide how much energy you have for your daily activities. Use the Fatigue Rating Scale to help judge how tired you feel. 0 means that you feel great, and 10 means you are too tired to move. For example, on a day when you think your fatigue rates a 2, you will probably be able to do more than on a day you rate your fatigue as an 8.



RATING SCALE

You can learn to cope with fatigue. Try to identify what makes you tired. Do you feel tired when you exercise? Feeling emotional or having anxiety can cause it. Do you feel tired all the time? Maybe you're not sure what triggers your fatigue.

You can identify what makes you tired using the chart below.

Activity	How I rate my fatigue (<i>fill in a number from 0-10</i>)
Dressing	
Bathing	
Eating	
Cooking	
Going up stairs (# of steps)	
Going to see doctor	

Plan your activities and rest periods. For example, eat breakfast first, and then allow for a rest period before you wash or get dressed. Build in rest periods between activities. Plan to do the most important things first, so that you have the energy to do them.

Depression and anxiety may affect how tired you feel. Speak with your health care provider or social worker if you are sad and unhappy often.

Fatigue

Tiredness

You can identify times to schedule rest and activity using the chart below.

Time	Activity / Rest Period
8 am	Eat breakfast
8:30 am	Choose a way to rest: Sit in a comfortable chair, read, watch TV, listen to music
9 am	Shower
9:30 am	Rest again with whatever relaxes you
10 am	Get dressed
10:30 am	Sit down and have a snack
11 am	Go for a walk
12 noon	Practice “Relaxation and Deep Breathing Exercises.”

This is just an example. You can make your own personal Daily Activity and Rest Schedule by filling in the chart below.

Your Own Personal Activities and Rest Schedule

Time	Activity / Rest Period

Fatigue

Tiredness



III If you are not sleeping well:

- A** Keep a log on how well you sleep. Note what helps you sleep better and also what interferes with your sleep.
- B** Ask your health care practitioner for ideas or medications to help you rest.
- C** Avoid caffeine near bedtime. Try herbal, non-caffeinated tea, like chamomile.
- D** Try not to stay in bed for long periods. Your muscles may get weak and you may have trouble sleeping at night.
- E** Avoid taking a nap within 6 hours of bedtime.
- F** Wear earplugs or listen to soothing music.
- G** If pain wakes you up, talk to your health care provider about medication to relieve pain.
(See page 50-52 on Pain).



Try these deep breathing and relaxation exercises to help you sleep:

1. Close your eyes and think about your favorite place. It should be a place that makes you feel good inside, like a beach or a place in the country.
 - See yourself in this place
 - Smell the scents
 - Hear the pleasant sounds
 - Feel the warm breeze, the coolness of the water (or whatever surrounds you in your favorite place).
2. Breathe in and out, slowly and deeply.
3. Think about relaxing. You can say to yourself, “I am relaxing. I can feel my whole body relaxing.”
4. If it helps, you can count while you breathe. For example, when taking in a deep breath you can count “air in, one, two, three” and then “air out, one, two, three.”
5. You can do this for a few minutes or as long as you’re comfortable.

Shortness of Breath

If you notice any shortness of breath that is new, or worse than you have had before, let your health care provider know. It could be a sign of an infection in your lungs, especially if you have a temperature greater than 100°F. Any change in your breathing is important.

When you feel short of breath, it is helpful to:

- A** STOP what you are doing and rest until you catch your breath.
- B** Try not to panic. Not being able to catch your breath is scary for anyone. Try to focus on relaxing.
- C** Take walks at your own pace in areas where you know there are benches to rest such as a park or a shopping mall.

Use what is called ‘pursed lip’ breathing to ease your shortness of breath. Pucker or purse your lips to do this. Imagine yourself smelling flowers as you breathe in through your nose slowly to a count of two, and blowing out candles as you breathe out to a count of four.



Pursed Lip Breathing

Try this way of breathing, and you will probably notice yourself catching your breath. This can help you cope with the fear and may help calm you.

Shortness of Breath

It is not unusual to feel frustrated or anxious when you are short of breath. It may prevent you from doing even simple tasks.

Learning new ways to relax can be helpful. Try these relaxation and deep breathing exercises:

A Close your eyes and think about your favorite place. It should be a place that makes you feel good inside, like a beach or out in the country.

- See yourself in this place
- Smell the scents
- Hear the pleasant sounds
- Feel the warm breeze, the coolness of the water (or whatever surrounds you in your favorite place).

B Breathe in and out slowly and deeply.

C Think about relaxing. You can say to yourself, “I am relaxing, I can feel my whole body relaxing.”

D Focus on breathing slowly and evenly. If it helps, you can count while you breathe “air in, one, two, three” and then “air out, one, two, three.” You can do this for a few minutes or as long as you’re comfortable.

E Listen to relaxing music or do any other activity you enjoy.

Note: Reporting shortness of breath to your health care provider is important, especially if it prevents you from doing daily activities. If it becomes worse, seek immediate help if in distress.

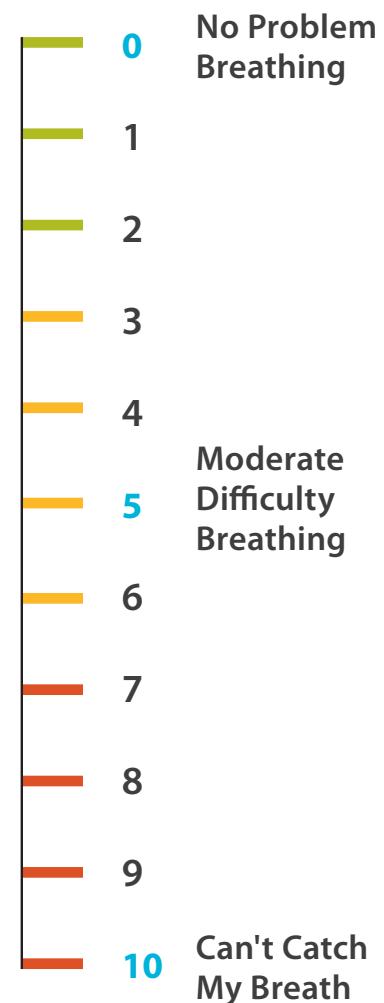
Breathing Rating Scales

A self-rating scale can help you decide how well you are breathing and able to function that day. Use the Shortness of Breath Rating Scale to help figure out how well you are breathing. ‘0’ means you have no shortness of breath or no problems breathing, ‘5’ means you’re having moderate difficulty breathing and ‘10’ means you cannot catch your breath. For example, on a day when your breathing rates a ‘2’ you will probably be able to do more than on a day you rate your breathing as a ‘6’.

Try to identify what makes you short of breath. Do you feel short of breath when you exercise? In some people, anxiety or feeling emotional can cause it. Do you feel shortness of breath all the time? Maybe you’re not sure what triggers your shortness of breath.

You can identify what makes you short of breath using the number scale on the right.

BREATHING SCALE



RATE YOUR ACTIVITIES

Activity	How I rate my breathing (fill in a number from 0-10)
Dressing	
Bathing	
Eating	
Cooking	
Going up stairs (# of steps)	
Going to see doctor	
Anxiety	
Exercise	

Shortness of Breath

Plan your activities and rest periods. For example, eat breakfast first, and then allow for rest before you wash or get dressed. Build in rest periods between activities. Plan to do the most important things first, so that you have the energy and breath to do them.

Sample: Daily Activity and Rest Schedule

Time	Activity / Rest Period
8 am	Eat breakfast
8:30 am	Choose a way to rest: Sit in a comfortable chair, read, watch TV, listen to music
9 am	Shower
9:30 am	Rest again with whatever relaxes you
10 am	Get dressed
10:30 am	Sit down and have a snack
11 am	Go for a walk
12 noon	Practice “Relaxation and Deep Breathing Exercises.”

This is just an example. You can make your own personal Daily Activity and Rest Schedule by filling in the chart below.

Your Own Personal Activities and Rest Schedule

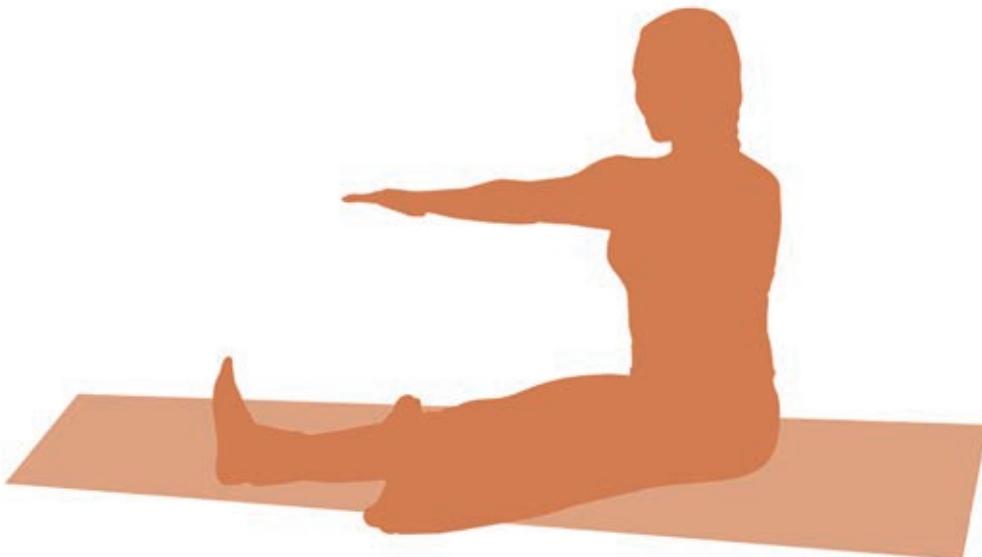
Time	Activity / Rest Period

Shortness of Breath

You can learn to cope with shortness of breath. Increase the amount of sleep you get, even with cat naps. Eat healthy foods. Food provides fuel for energy. If you want energy, you have to put food in your body. Small, frequent feedings are probably a better choice than three heavy meals, especially if you feel short of breath. You use less breath when the meal size is smaller.

Try to exercise regularly. Exercise can help you to strengthen muscles, build endurance and control shortness of breath. Exercise can also improve how you feel. You will probably feel better when you see that you can do more. Exercise improves how well your body uses oxygen. You don't have to jog or join a gym. Simple exercises include:

- Stretching your arms and legs when you get out of bed
- Walking up and down stairs, even if you start with only two or three steps. Try to increase the number of steps each time you do it.
- Sitting in a chair and holding a can of food in each hand while extending and flexing your arms.
- Taking a walk, going a little farther each time.



Ask your health care provider which exercise is best for you.

Chronic Cough

If you are coughing more than usual, or have a new cough, let your health care provider know right away. It may mean that you have an infection in your lungs, especially if you have a fever above 100°F.

It is important to have your health care provider check any new or worsening cough. If you have night sweats, let your provider know right away.

When you cough, cough into a tissue or your elbow to avoid spreading germs. If your mucus has a color to it, notify your health care provider. This could mean you have an infection. Often, this is easily treated with antibiotics.

Cold air can cause you to cough. You can lessen the effect of cold air by covering your mouth with a scarf.

To ease coughing spells:

- Sit up.
- While sitting in a chair, place a pillow on the table in front of you and lean forward on to the pillow. Place your arms just beyond where you lay your head.
- Use cough drops.
- Consult with your health care provider or pharmacist about using cough medicine. The cough medicine that is best for you depends on whether you have a dry cough or a productive cough. (A productive cough means you have mucus along with your cough.) Take your cough medicine according to directions from your health care provider.
- Drinking clear fluids can sometimes help loosen mucus, making it easier to cough up. Warm tea with honey may help soothe your throat. Gargling with warm salt water can also help relieve a sore throat.

Ask your health care practitioner whether there is any possibility that gastric reflux can be making you cough. This means that your stomach fluid is backing up and causing you to cough.

Relieving Pain

When you feel pain in any part of your body, tell your health care provider about it. Ask them for ways to relieve it. Pain is real. It is not imagined. Continue to mention your pain to your health care provider until you get relief. You have the right to be pain free.

Pain Rating Scale

It's just as important to report pain as it is to have your blood pressure and temperature checked. A Self-rating Pain Scale can help you express how much pain you have. Think about how strong or intense your pain feels, and see what number matches your pain. "0" means you have no pain at all and "10" means you feel the worst pain possible. Review your ratings with your provider so they can help determine the best relief for you.

There are different kinds of pain. Pain in your internal organs can feel like cramping, squeezing, crushing, gnawing, tightness, pinching or pressure. It may move around and be difficult to know where it's coming from.

Often pain in your muscles or bones feels aching or throbbing, and is usually felt in one place.

With nerve pain you may feel numbness, burning, shooting, itching, stinging or tingling, like pins and needles.

RATING SCALE



Relieving Pain

Talk to your health care provider about medications you have taken to relieve pain:

- Which medications work
- Which medications do not work
- Which ones have caused side effects or allergic reactions

Make sure your health care provider knows all the medications you take (prescribed and over the counter), including any herbs or other remedies.

What You Can Do To Relieve Pain With Medication:

- Remember that the best way to treat pain is to prevent it.
- Take your pain medication on a scheduled basis. Do not wait until you are in agony to try to relieve your pain. If you wait until you're in extreme pain, the medication doesn't work as well. Remember, pain is not good for your body.
- Keep your health care practitioner informed about how much relief you get. It may take several tries to manage your pain. This is not unusual.
- Keep a diary of your pain rating and how you describe it. Note how it changes as your pain is relieved. Include the date, time, name and amount of any medication you take. This helps you and your provider decide how well your medicine is working. It is also a way for you to show your health care practitioners how often you experience pain, what it's like, and how much relief you feel.
- Certain kinds of pain may be relieved by medications that are not usually known as pain relievers. Even some anti-depressants relieve pain, so don't be surprised if your practitioner gives you a medication that is not a standard pain reliever.
- Medications to relieve pain may cause constipation. If you cannot move your bowels easily or on your usual schedule, let your health care practitioner know. See page 37 on Constipation for further information.

Other Ways of Relieving Pain



Try deep breathing and relaxation exercises. They may help soothe your symptoms and calm anxiety. For example:

- A** Close your eyes and think about your favorite place. It should be a place that makes you feel good inside, like a beach or somewhere out in the country.
 - See yourself in this place
 - Smell the scents
 - Hear the pleasant sounds
 - Feel the warm breeze, the coolness of the water (or whatever surrounds you in your favorite place).
- B** Breathe in and out slowly and deeply.
- C** Think about relaxing. You can say to yourself, “I am relaxing. I can feel my whole body relaxing.”
- D** If it helps, you can count while you breathe. For example, when taking in a deep breath you can count “air in, one, two, three” and then “air out, one, two, three.”
- E** You can do this for a few minutes or as long as you’re comfortable.

Listen to music you enjoy. Read a book or magazine. Watch a movie. Laugh. Use pillows to support you in bed. Hug a pillow to relax your arms. Support your back with a pillow. Use a special bed surface to prevent skin breakdown, especially if you have lost a lot of weight. Try heat or cold at the site of your pain, whichever works best for you. Massage and/or acupuncture may also help.

Note: Remember to communicate with your health care practitioner. Let them know whether your pain is being relieved. Remember, you have the right to pain relief.

Weakness in Arms or Legs

I Weakness in your arms may prevent you from carrying out your daily activities. Weakness in your legs can cause difficulty walking and can be frightening. If you develop weakness in either your arms or legs, let your health care practitioner know. They may want to have a physical therapist evaluate your situation. Things you can do to make your home safe include:

- A** Remove area or throw rugs. Even if you nail them down you could still trip over them.
- B** Use a tray to carry hot liquids or food from the stove or microwave to the table. Only fill containers halfway to avoid spilling and possibly burning yourself. If possible, ask someone else to bring your food to the table.
- C** Never smoke in bed. This is very dangerous. If you start a fire you may be too weak to get away quickly enough.

II If you have areas of decreased sensation in your arms or legs, be careful and:

- A** Protect them by not wearing tight fitting clothes or shoes. Check inside of shoes before putting them on.
- B** Avoid sitting too close to radiators or heaters.
- C** Avoid using heating pads.

III Ask your health care provider about getting assistive devices such as:

- A** A cane or walker
- B** A shower chair
- C** Grab bars for the tub or shower
- D** A hand-held shower head
- E** A urinal or commode so you won't have to get up during night

Exercise will help strengthen your muscles. Ask your health care provider or physical therapist about a home exercise program to help strengthen your arms and legs. Walking is good exercise. Even lifting heavy books or cans of food can help build upper arm strength.

Fever



I Fevers can occur throughout the course of HIV illness and should always be reported to your health care practitioner. A fever is generally considered to be a temperature over 101 degrees Fahrenheit.

Things you should do when you get a fever include:

- A** Take medicine such as Tylenol or ibuprofen to bring the fever down (ask your practitioner which is better).
- B** When in bed, use a sheet and a loosely woven blanket to cover yourself. This will allow heat to escape from your body without allowing you to catch a chill. Try to stay warm.
- C** Keep your clothes and bed linens dry. Change them if they become wet from sweating.
- D** If you want, you can take a tub bath (if you have no sores on your body). Make sure your room is very warm. The bath water should be about 1 to 2 degrees less than your body temperature as measured by a thermometer. After you finish, dry off thoroughly, go to bed and get under the covers.
- E** Do not use alcohol or tepid (room temperature) sponge baths because you might start to shiver. Anything that causes you to shiver will make your temperature go even higher.
- F** If you have chills and are shivering, get into bed and keep warm.
- G** Having a fever uses a lot of calories. If you feel up to it, eat six small, high protein, high calorie meals a day. If your appetite is poor, try drinking a homemade milkshake like those listed in the Nutrition section on page 31.
- H** Drink at least 6-8 glasses of fluid a day – unless you are on a fluid restricted diet.



II If your temperature doesn't come down, you should contact your health care provider. Fevers that do not go away can be very dangerous. Do not wait, because some people get confused with high fevers.

III If you have a recurrent fever at night you can manage the problem by:

- A Taking prescribed anti-fever medication before you go to sleep. Keep an extra dose near your bed so if you need it you won't have to get up and look for it.
- B Keeping a bottle of water next to your bed.
- C Placing a towel over your pillow, so if you sweat during the night, all you have to do is remove the towel in order to have a dry pillow. Keep an extra towel nearby in case you need it.
- D Having a change of bed clothes nearby.

Vision Problems

- I **Always report any changes in your vision to your health care practitioner immediately. In some instances, the problem is caused by an eye infection and the earlier you get treated the less likely you are to have significant loss of vision.**
- II **Here are some suggestions to help you if you are having problems with your vision.**
 - A Keep a night light on when you go to bed at night.
 - B Use a tray when you eat meals. Place everything you are going to eat on the tray. This will give you boundaries around your food and utensils that you can feel.
 - C If friends visit and they happen to move something, ask them to put it back before leaving.
 - D If you use a cane, always bring it with you outdoors and leave it extended (not folded up). This helps people understand that you have vision problems so they don't bump into you.
 - E If you need help when crossing a street, don't hesitate to ask for assistance. People will usually help, especially if they see your cane.
- F Use an electric razor to shave. File your nails instead of clipping them.
- G Pre-pour boxes make it easier to take your medicines. Ask your provider about an alarm watch to help you remember to take your medications on time.
- H If you have a tape recorder, ask your health care provider to record instructions during the visit.
- I Some people feel having a shorter haircut is easier to manage.
- J Don't be surprised if people talk loudly when they discover you have a vision problem. We know it makes no sense, but people do it. Remind them that you can hear and they don't have to shout.
- K If you're interested in organizations that help people with vision problems, you can contact the Jewish Guild for the Blind at (212) 769-6200 and also Lighthouse International at (212) 821-9200 or toll-free (888) 222-9320.
- III **If light bothers your eyes you can:**
 - A Wear sunglasses when you go outside.
 - B Keep the lights dim in your home.
 - C Wear a hat with a brim, like a baseball cap, when you are outside.
 - D Keep your television at a low level of brightness.

Mouth Problems

I Review basic mouth care
(See page 25, Section II).

II Thrush is caused by a fungus called candida albicans. There are medications to treat thrush. Ask your health care provider which is best for you.

III To prevent and control thrush:

A Eat 1 to 2 containers of yogurt daily. Yogurt may prevent this fungus from overgrowing. The label should read Lactobacillus acidophilus or L. acidophilus.

B If you don't like yogurt, you can get lactobacillus acidophilus capsules at any health food store.

C Rinse your mouth at least three times a day with homemade mouth wash. You can make this by:

- Adding one-half teaspoon of salt and one-half teaspoon of baking soda to one quart of warm water (change this solution daily).
- After using the solution, rinse your mouth with cool water.

D Some people find that using apple cider vinegar, diluted with water, helps to prevent or get rid of thrush.

IV For mouth pain:

A Use straws to drink liquids.

B Popsicles, ice cream, and ice cubes may numb mouth pain.

C Eat foods at room temperature and avoid very spicy foods.

V For dry mouth:

A Because certain foods may irritate a dry mouth, try avoiding: very hot or very cold foods, spicy foods, dry or hard foods and citrus juices.

B Strong commercial mouthwashes can also irritate a dry mouth. Try substituting the homemade mouthwash made from water, salt and baking soda mentioned in section C.

C Drink water throughout the day. When away from home, take a small plastic bottle of water with you. At night, keep a pitcher of water near your bed.

D Suck on sugarless hard candies or chew sugarless gum.

E Use lip balm to keep your lips moist.

VI Report any new mouth problems to your health care practitioner. If your gums start to bleed, do not use aspirin or aspirin products because they make you bleed more.

Skin Problems

Skin problems are common. Report any rashes, itching, lumps, bumps, growths, blisters, or changes in skin color to your health care provider. Review basic skin care (page 25, Section I), especially if you have dry skin.



Managing skin infections

- A** If you have sores or breaks on your skin, don't take tub baths. Instead take a shower. Some sores, caused by viruses, can spread to other parts of your body through the bath water.
- B** Use a separate washcloth to clean the areas of your skin where there are sores.
- C** Avoid scratching areas where the skin is broken (you can spread infection). Ask your health care provider if you should cover any sores with gauze.
- D** Fungal infection of the skin is a common problem in people living with HIV. You may notice areas in your groin and inner thighs or on your buttocks that are red and itchy. Things you can do to control and prevent these problems include:
 - 1.** Using an antifungal powder or cream every day. You don't need a prescription and can buy these products at any drug store. Ask the pharmacist to point them out.
 - 2.** Eat yogurt every day. Believe it or not, yogurt helps prevent skin problems that are caused by fungus. Make sure to check the label when you buy yogurt. It must say 'Lactobacillus acidophilus or L. acidophilus'. If you don't like yogurt, you can buy L. acidophilus capsules in a health food store.

Skin Problems

|| Shingles

If you have had chickenpox in the past, you may be at risk of getting shingles. Shingles is a viral illness that is caused by the same virus that causes chickenpox so it can be spread to people who have not had chickenpox or the chickenpox vaccine.

If you have shingles, try to avoid contact with people who have never had chickenpox or the vaccine, especially during the first 3 days of the illness.

A Signs of shingles:

- Painful rash on one side of the body or face. Pain may be burning or shooting, and can be mild to severe
- Rash may form blisters
- Tingling or itching

B Shingles eye infection may lead to vision loss. See your health care provider immediately if you get shingles in or around your eyes.

Your health care provider can give you medications to control the infection and reduce the severity of the disease. These medications work best if started within 3 days of getting the first sign of shingles. You may also be given pain medications to treat severe pain. Pain may continue even after the rash is gone.

What to do when blisters form:

- Keep the area clean and dry
- Keep the area covered
- Avoid scratching the area. Anti-itching lotion may provide some relief
- Wash hands often
- Place a cool wet compress on area to relieve pain and itching

Notify your provider if you develop redness around the rash. This may be an infection that is easily treated.

Skin Problems

III Genital Herpes

- Is a sexually transmitted disease caused by a virus
- Can be treated; see your provider if you have any signs of an outbreak
- You can get genital herpes from someone who is infected even though they may not have a visible sore and may not know they are infected
- May cause blisters on or around genitals, rectum or mouth
- Some people have no symptoms at all; or symptoms are very mild
- Always use a condom to help prevent passing the infection to your partner, even when there is no visible sore. Remember, it is possible to pass on the infection when there is no visible sore.
- Treatment also helps to prevent passing the infection, but neither condoms nor treatment is 100% effective in preventing transmission.

IV Pressure ulcers and skin breakdown

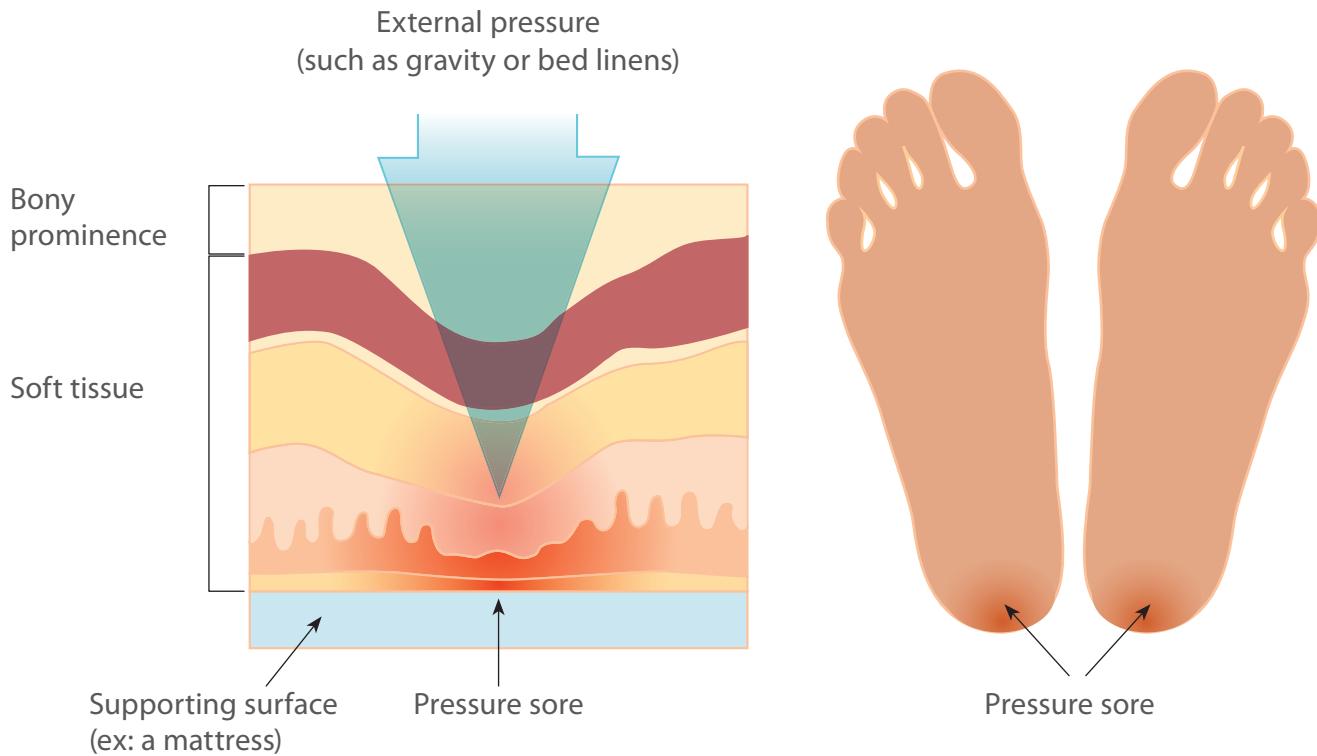
A If you have problems controlling your bowels and bladder:

- Sometimes people have trouble controlling their bowels because of infections. If this happens, you can use baby wipes to clean your skin. Carry them with you when away from home. Keep this area clean to help prevent skin breakdown.
- Use disposable liners or shields in your underwear to absorb moisture and keep your clothes clean.
- Use Vaseline to protect your skin from urine and feces.

B If you are in a wheelchair, or sit in a chair most of the time:

- Reposition yourself at least once every hour.
- Shift your weight every 15 minutes.
- Ask your health care provider about pressure-reducing devices for you to sit on.
- Try to distribute your weight evenly; don't lean continuously on one side.
- Consider using pillows to add support and comfort.

Skin Problems



C If you spend all or most of the day in bed:

- Reposition your body at least every 2 hours. For example, if you are on your right side at 8 am, switch to your left side at 10 am, and at 12 noon lay on your back. This will help prevent bedsores.
- Use pillows or a folded cotton towel to keep the bony parts of your body from touching (like between your knees).
- Ask your primary care provider about getting an “alternating pressure pad” for your bed.
- Keep your heels off the bed so you don’t get sores on the heels of your feet. Put a pillow under your ankles to keep your heels off the bed.
- If you need help turning in bed, don’t let people drag you across the sheets. This can damage your skin.
- Use lotion on your skin to keep it moist and prevent breakdowns.
- If someone gives you a backrub, tell them not to massage areas of skin over bony areas that are red. This is not good for your skin.
- When you are in bed, do not raise the head of the bed higher than 2 feet to prevent sliding down in bed. The exception is when you eat; then you should be sitting up.
- Good nutrition is very important to keep your skin in good shape. If you are not eating enough protein, you may begin to develop skin problems.

Sleep Problems



To help you sleep at night, consider the following:

- A** During the day, try not to lie in bed to watch TV or read. Save the bed for sleeping in at night.
- B** Try to exercise every day.
- C** If you watch TV before going to bed, try not to watch shows that excite or upset you. They may be entertaining, but falling asleep afterwards might be difficult.
- D** Keep a urinal or a bedpan by the bed so you don't have to go all the way to the bathroom.
- E** If you turn down the ringer volume on the phone, leave a note on the phone reminding you to turn the volume back up when you wake up.
- F** Have anything you might need during the night next to your bed, such as tissues and something to drink.
- G** Try to avoid eating or drinking anything containing caffeine, such as chocolate, coffee or cola around bedtime.
- H** If you're having trouble falling asleep because you feel overwhelmed or stressed out, there are many support groups in New York City for people living with HIV.

Sleep Problems

|| Before getting into bed:

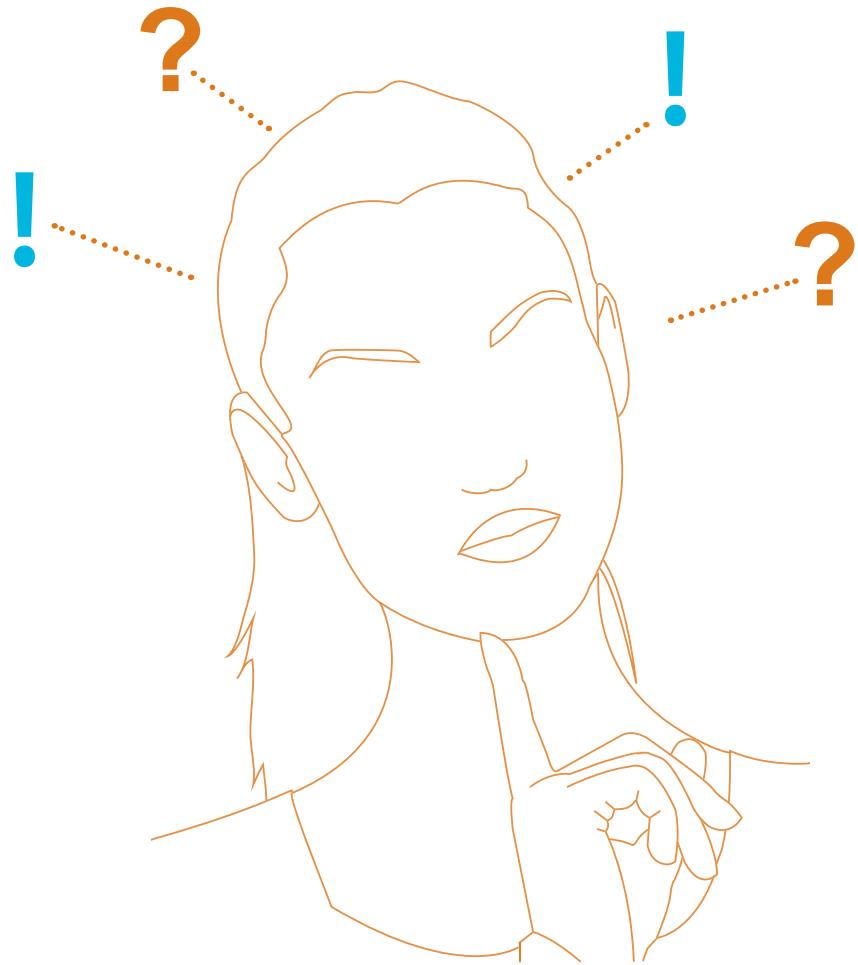
- A** Take a warm shower. It may help relax you.
- B** Listen to soft music.
- C** Read a book or magazine.
- D** Drink warm milk or herbal tea.

||| When you get into bed, you can try this Deep Breathing and Relaxation Exercise to help you sleep.

- A** Close your eyes and think about your favorite place. It should be a place that makes you feel good inside, like a beach or somewhere out in the country.
 - See yourself in this place
 - Smell the scents
 - Hear the pleasant sounds
 - Feel the warm breeze, the coolness of the water (or whatever surrounds you in your favorite place).
- B** Breathe in and out slowly and deeply.
- C** Think about relaxing. You can say to yourself, “I am relaxing. I can feel my whole body relaxing.”
- D** If it helps, you can count while you breathe. For example, when taking in a deep breath you can count “air in, one, two, three” and then “air out, one, two, three.”
- E** You can do this for a few minutes or as long as you’re comfortable.

Note: If none of these suggestions help you get a peaceful night's rest, speak to your health care provider about medications to help you sleep.

Problems with Memory and Concentration



Sometimes people living with HIV infection develop memory problems. They might forget things that they would usually remember. They may find it hard to concentrate or suddenly get confused. This can be embarrassing or even scary. If you notice this happening, tell your health care practitioner about it. It may be possible to treat this.

II Things that you can do to improve and manage the situation include:

A Stay as active as possible by:

- 1.** Joining a support group for people with HIV/AIDS.
- 2.** Spending more time with family and friends.
- 3.** Getting out of your apartment every day, even just to go for a walk.
- 4.** If someone cooks for you, you can participate in making shopping lists or planning meals.
- 5.** Try to get some exercise each day. If you are able, you can help with activities around the house.
- 6.** Do puzzles such as crossword, Sudoku, or KenKen.

B Watch television every day, especially the news, so you keep up with what is happening.

C Keep a calendar visible and mark off each day to remind you what day it is.

D Wear a wrist watch so you know what time it is.

E Get dressed every day and continue your usual grooming activities such as shaving or putting on makeup.

F If you are having trouble remembering to take your medication:

- 1.** Use a pill box, medication reminder, alarm watch, or cell phone alarm to help you keep track of when to take your medications.
- 2.** Keep your medicines where you can see them during the day so you don't forget to take them.
- 3.** If possible, ask for help from family or friends.

G Lack of sleep may contribute to memory loss. If you are having difficulty sleeping see page 62 on Sleep Problems.

III Things to avoid include:

A Letting people around you do everything for you.

B Sitting around the house all day in your pajamas.

C Isolating yourself from friends and family.

D Not exercising.

Coping with Illness and Depression

- I If you are having problems coping with your illness, let your health care provider know. Worrying all the time can cause fatigue, weight loss and other problems, including depression.
- II Depression can come and go or it may get worse. Sometimes it lasts for a while. Symptoms of depression can include:
 - A Loss of interest in things you used to enjoy
 - B Feeling sad, blue, or down in the dumps
 - C Feeling worthless or guilty
 - D Problems concentrating, thinking, remembering, or making decisions
 - E Loss of energy or feeling tired all the time
 - F Increase or decrease in appetite
 - G Trouble sleeping
 - H Avoiding contact with family and friends
 - I Feeling hopeless or helpless
 - J Thoughts of suicide or death

III Things you can do to prevent or cope with depression include:

A Discuss your feelings with others.

- There is a wide range of support groups available in all boroughs of New York City. These groups can be helpful, and you will see that you are not alone with your feelings. It may help you learn new ways to deal with these feelings.
- If you are unable to leave your home, ask your health care provider about in-home counseling.

B Medication has been successful in helping many people cope with their depression. You can discuss medication options with your health care provider.

C Include some form of physical exercise in your daily activity. If you can get out, go for a walk every day. If you can't leave your home, walk around the apartment several times. Even if you are in bed, you can exercise your arms and legs every day.

D Don't avoid your family and friends. Ask them to visit frequently. Even if you think you're not up to it, make an effort. Remember, the people who love you want to see you.

E Take it slow. When people get depressed, they are often not able to do the things they usually do. Be patient with yourself.

H Avoid street drugs and alcohol. These can make depression worse as well as interfere with the medicines you are taking.

I Avoid making any major life decisions when you are depressed. It's best to ask someone you trust for advice about major decisions.

Note: Thoughts of suicide and death are often a part of depression. You are not alone; many people with chronic illness have these thoughts from time to time. If you have these thoughts, you should tell someone you trust. Ask them to help you find professional help right away.

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SELF-CARE GUIDE